

00;00;00;14 - 00;00;06;05

Steven Molony

Hello and welcome to Chronically Complex, the Official #MEAction Podcast. I'm Steven Molony.

00;00;06;11 - 00;00;24;01

Jaime Seltzer

And I'm Jaime Seltzer. I'm a person with ME and ME runs in my family with my mom and sister both affected. I'm the director of Scientific and Medical Outreach here at #MEAction, and I do research at Stanford University on ME/CFS and other chronic complex diseases.

00;00;24;24 - 00;00;46;14

Steven Molony

I'm an actor, writer and filmmaker. I'm also the guy that makes all of #MEAction's videos and I provide a lot of voiceover as well. I don't personally live with any chronic illnesses, but I have some dear friends who suffer with myalgic encephalomyelitis and other chronic diseases. I want to be a better ally and I'm looking forward to getting to chat with the truly amazing people we're going to be bringing on to this podcast.

But before we get started, let's give a shout out to our sponsors. This episode is brought to you by Outside In Theatre. Outside in is an evolving force in equitable and transformative storytelling through multi-platform theatrical experiences. Outside In produces daring, dynamic and authentic work that speaks to the intersectional communities and amplifies content created by and for unrepresented voices.

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00;01;26;17 - 00;01;55;26

Jaime Seltzer

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And we know the value of their work firsthand. Check them out at thegoodmancenter.com. And now I'd like to introduce our next guest, Fiona Lowenstein.

00;02;08;04 - 00;02;33;24

Steven Molony

Fiona is an award winning independent journalist whose works have been published in The New York Times, Vox, The Guardian, and many other publications. In 2018, they founded Body Politic, a queer feminist wellness collective and events series, which has become a grassroots, patient led health justice organization. Then in 2020, they co-founded Body Politic's, COVID-19 Support Group, which serves over 11,000 COVID-19 patients.

Most recently, Fiona embarked on a book project, The Long COVID Survival Guide, now available for preorder.

00;02;41;04 - 00;02;57;00

Jaime Seltzer

Fiona and I have been mutuals on Twitter for a while and we've had a lot of interesting conversations in there and via email, but we've never actually met before. I'm really looking forward to engaging with them on the show. So let's get started.

<Theme music plays>

00;03;02;18 - 00;03;18;10

Steven Molony

Welcome, Fiona, to Chronically Complex. I would love to know your Long COVID story if you wouldn't mind diving into that. Can you just describe your experience with COVID-19 and realizing that your symptoms were just going to be sticking around?

00;03;18;28 - 00;03;51;23

Fiona Lowenstein

Yeah. Yeah. And thanks for for having me here. I'm excited to get the chance to talk with people I have been admiring on the Internet for a while. I got sick at the very beginning of the official first wave in the United States. And I say official because we now know that there were COVID patients in the US before March of 2020, but I was living in New York City at the time, got infected, I believe on March 10th the friend came over for dinner and this was of course, before we were being told to stay home or mask.

And she kind of got sick before my eyes, got very pale and said, I don't feel well.

And she was supposed to spend the night. And we decided, you know what, just to be safe, you go home and I think I, like, Lysol-wiped a couple of things in the apartment but you know, we really didn't think it was something that was going to affect us.

And, in fact, at the time, we were planning because body politic existed before the pandemic as a queer feminist wellness collective, we were planning how body politic could support the needs of people who would be at risk for severe COVID, which at the time we thought would mainly be elderly people and people who are immune compromised. We were talking about all these--

Could we have as some sort of affinity groups for people who have undergone cancer treatments or resources? But then we ourselves got sick. She got sick a couple of days before I did. I got sick. My partner got sick. And all of our experiences did not match the mainstream narrative for what we as relatively, quote unquote, healthy 20 somethings should be experiencing.

So I was the only one who had severe shortness of breath. And so I was the only one who got access to in-person health care because New York City was so overwhelmed. My friend was in another borough. She also didn't have a primary care provider who she'd been working with for years like I did. And so she just did not have the same resources to get treated.

So she was struggling to talk to doctors and and try and figure out what was going on. But because she didn't have that shortness of breath, she wasn't taken as seriously. I was hospitalized very briefly. I was not intubated. I would just receive supplemental oxygen. And I was very eager to leave the hospital. They made it clear to me that the hospital was a pretty terrible place to be at that point.

The nurses were like, more and more people are coming in. It's getting very overwhelmed. And so as soon as my fever broke, and my shortness of breath had improved even slightly. They sent me home and it was after I got home that I noticed that I couldn't smell anything. I don't know if that had happened before or after.

It was honestly not top of mind when I was in the hospital and then over the coming days and weeks, other symptoms emerged. So, you know, at the beginning, it had really just been fever and shortness of breath with a little bit of cough. But I started to develop very debilitating gastrointestinal issues, fatigue, migraines that were sometimes-- sometimes these symptoms were following, you know, kind of quote unquote, "periods of exertion."

I wasn't doing that much at that point in time, but I would like do an interview because I was a writer and I was writing about what was going on. And after the interview I would be on the couch with a blindfold on, unable to watch TV because the light hurt my eyes, feeling a sore throat and all this fatigue.

And it went on that way for a pretty long time without much improvement. There were changes happening, but it sort of just seemed like more symptoms were showing up. And I was lucky to be able to take a lot of time off from work. I basically just used up all of my savings during that time to not have to work and rested a lot.

And then I started to feel like I had recovered a couple of months later, but I had not fully recovered. In retrospect, I got to a point where I was able to return to work without significant after effects, and I was still working from home and had a relatively flexible schedule. Got to the point eventually where I was able to exercise a little bit regularly, but then I had really severe menstrual symptoms.

I sit here before you now, I would say like much more on the recovered end of the spectrum of Long COVID experiences, but there's still a lot of things I'm doing to kind of keep my body functional on a day to day basis that I'm also aware I wouldn't be able to do if I didn't have work from home privilege and live with a very supportive partner who is able to pick up housework and chores when I'm not able to and that sort of thing.

00;08;07;01 - 00;08;09;17

Steven Molony

That's huge. Yeah, I'm glad you have that support.

00;08;09;17 - 00;08;10;29

Fiona Lowenstein

Yeah, it's crucial.

00;08;11;15 - 00;08;19;27

Steven Molony

Yeah. You know, and you mentioned Body Politic, and of course, we want to ask you all about that. What made you start it?

00;08;19;27 - 00;08;41;24

Fiona Lowenstein

Yeah. So early on in the in the pandemic, when I was sick and my friend was sick, but no one else really seemed to understand that this type of illness could exist in people that were that were younger. I... Well, let me say-- Let me think, actually. Okay. So when I got home from the hospital, I wasn't really talking to anyone.

I had very little energy. It was hard to speak at first as well because of the shortness of breath. After about a week, I felt like I had the energy to have a FaceTime conversation with my friend who had infected me. And in that conversation we were both sharing symptoms with each other that we had not seen listed anywhere else.

So I at the time thought that my gastrointestinal issues were a result of food poisoning. I thought that the new congestion I had in my nose and my sore throat must be seasonal allergies come early. I really did not think these things were connected to COVID because I was trying to trust the advice I had been given. And when I was in the hospital, I had been told flat out by a nurse when I told her about my partner was having GI issues that, oh, they can't have COVID because GI issues are not a part of COVID.

Again, this was March, March 14th, 2020. So there was hopefully more misinformation circulating then than there is now.

00;09;40;20 - 00;09;42;06
Jaime Seltzer

We would hope.

00;09;42;19 - 00;10;01;28
Fiona Lowenstein

Yeah, yeah, yeah. You never know. But when I had that first kind of patient conversation with Sabrina, who is the person who I think infected me? She was saying that she had GI issues and she was saying that she had a really sore throat and all of these kind of other-- we both had rashes and hives.

They were just symptoms that, again, I had chalked up to other things, but she was experiencing them too. And she had found, I think, a couple of tweet threads, one from an actor who was having GI issues and we we together found a very small local story about a cruise ship passenger who had had GI issues as well.

So we were like, okay, maybe this is related. You know, doing the detective work. But what also became clear was, I mean, that conversation we had with each other, we were both exhausted by it.

We could barely participate in it, but it was the most helpful thing that had happened in the entire experience of being sick, because it was the first time that we were actually talking to someone who could understand what we were going through.

And we had breakthroughs on the call in terms of just realizing, Yeah, these symptoms are COVID related and we're not just getting better immediately and maybe we're not the only ones. And so we kind of said, you know, there are other patients out there who should get this. I wish we could give this experience to other people. And I had written an op ed in The New York Times very shortly after I was discharged from the hospital.

I felt like I had gotten a window into the front lines of this huge current event, and I needed to share some of the information that I had learned from my experience. And so I had just written an article about being young and otherwise healthy and being hospitalized and how COVID might be more serious for young people than we imagined.

And all of these younger COVID patients that connected with me on social media. So I was already having some conversations with people who were similarly saying, how did you get care at the hospital? What did they do for you? Are there any treatments? Lots of questions. And people were sharing information with me that was sometimes helpful, vice versa.

I actually even met up with someone in person, you know, distance to hand over a spare thermometer. I met this person online, so we knew that there were people out there who needed the support. So we thought, well, why not? We have Body Politic as a platform already. We have a few thousand Instagram followers. Why don't we just share a Google sign up form and people can put in their email addresses and we'll start a little Instagram chat group chat so that I don't need to be individually contacting all of these people who have connected with me.

But then, of course, it became much larger than that eventually.

00;12;21;15 - 00;12;53;05

Jaime Seltzer

Yeah, absolutely. You know, having body politic around in 2018 ended up being an enormous boon just by total chance. Right. And the fact that it was an organization that was centered around advocacy and, you know, that has to have really sort of helped lay the groundwork for what ended up being one of the biggest forces, social and and scientific forces in Long COVID.

00;12;54;09 - 00;12;55;16

Fiona Lowenstein

Yeah, I--

00;12;55;16 - 00;12;56;07

Jaime Seltzer

Go ahead, go ahead.

00;12;56;17 - 00;13;16;27

Fiona Lowenstein

I was just going to say, I think part of what helped was that we already, you know, Sabrina and I at least and a lot of the people that we met through Body Politic, we had a shared framework for health stuff in the sense that, for example, we'd done events on Fatphobia and the impacts of diet culture. We had done events where people had talked about medical gaslighting.

So these were not topics that we had to kind of say, Hey, do you believe this is true, right? The people who were setting up that group kind of had a shared political framework, I think. Which helped for sure.

00;13;30;20 - 00;13;53;23

Jaime Seltzer

Yeah, absolutely. And it has to have. I have often thought to myself that that was just a stroke of luck. I won't say luck, right. Because it's an enormous amount of work. But at the same time, still so lucky that the right skill set was in the right place at the right time. And you guys have gone on to help...hundreds of thousands?

I don't know how many people are on your mailing list at this point, but the number of people you've helped goes far beyond that number.

00;14;01;13 - 00;14;33;03

Fiona Lowenstein

Thank you. I am still like disbelieving of everything that happened in the past two years because, you know, I thought we were really big and doing a lot when like our 60 person events in New York City were being sold out in 2018 and 2019. So, you know, that moment when I wrote a second op ed on kind of Long COVID, I didn't know that that was what I was writing about at the time, but I wrote the second op ed after I wasn't getting better and I was connecting with other people who were still sick.

And I embedded the sign up form to the support group, and that was when we got like 2000 signups overnight. And that was the moment I think that Serena and I and other people that were working on this, it was a really small team at the time. Like three or four people realized, okay, this is going to be bigger than just getting an Instagram chat together.

This might actually have ripple effects that go beyond people who exist on Instagram.

00;15;00;14 - 00;15;03;09

Steven Molony

How does it feel to be part of such a groundswell like that?

00;15;03;25 - 00;15;33;24

Fiona Lowenstein

You know, it's what kept me going when it was really hard to think of other reasons to keep going. When I got sick in March and I was hospitalized, I felt overwhelmed. Honestly, I would say initially more by just the crisis that was taking place outside of my body. I felt like the city that I had grown up in, that my parents grew up in, that my grandparents grew up in.

Everyone I know pretty much lives in New York City. It was just under siege. And I would wake up in the middle of the night thinking, what about my kindergarten teacher? Like, How's she doing? Is she okay? Or You know, what about my old neighbor? Just these these thoughts of what's happening. And of course, that wave now pales in comparison to surges that happened afterwards.

But I felt so frustrated that I couldn't get out there and do something. I didn't know what I would be able to do, but I was sick. And so obviously I couldn't leave my home. And I kept thinking, maybe I'll get immunity and then I'll be like bike messengering, you know, groceries to elderly people. And I felt very just depressed that there wasn't-- that there didn't seem to be anything I could do to help and that I couldn't even go and comfort my parents or, you know, give them a hug in person.

And having this community and watching it grow was the thing that made me feel like I was doing something that made me feel like I was contributing. And it also gave me this intense sense of connection at a time where I lost a lot of connections, both in-person connections and just emotional connections with friends who really couldn't understand what I was going through.

So I feel very grateful and I think the most exciting thing for me has actually been watching what other people did with the platform because it's cool to create stuff and see it kind of blossom, but it's even more exciting when you create something and then someone else takes it and runs with it and does something else, which is what happened with patient led research and Long COVID

SOS and some of these other advocacy groups that were born out of that support group.

00;17;13;11 - 00;17;51;01

Jaime Seltzer

It's absolutely incredible. And I think that a lot of people who end up in advocacy, they see a problem like this and their urge is to figure out what they can do to help. And I only hope that there are lots more like you. So, you know, you've been in journalism and you are a journalist. And I'm wondering about your thoughts on how that work ties into concrete actions and changes for people with these often post-viral chronic complex diseases.

00;17;51;01 - 00;17;52;21

Jaime Seltzer

But maybe in general.

00;17;53;28 - 00;18;14;14

Fiona Lowenstein

Yeah. I mean, when I first got sick and when all of this started, I used the tools that I had to try to, I guess, do advocacy. I wasn't really thinking of it that way at the time. I typically don't think of myself as an advocate just because I studied journalism in college more and that's been more my role.

But I felt like the first step was just getting the information out there and I do think that raising awareness is often a first step from what I can tell for social movements and for justice movements. You have to help people understand what they're going through, right? And that they're not alone. If you can do that and sharing stories, whether it's your own story or other people's stories, is a great way to create kind of a consolidated group that is like, yes, we identify with this thing, we are together and we are going to mobilize together.

It's also helpful in terms of obviously raising awareness among people who are not directly impacted. I think that's something that is a much harder thing to achieve and has not fully happened. But that was a big part of my motivation behind writing these kind of early articles.

I was just thinking of every aspect of what I was going through and what I was seeing in the support group, whether it was losing friends or feeling better and then feeling worse and trying to think about how I could get it in different outlets.

But I think we saw, you know, when Ed Yong started writing about Long COVID in the summer of 2020, that brought a lot of attention to the illness. That was the first time that I heard anyone outside of the directly impacted community mention it. I think many people still didn't know what it was or still didn't fully understand it, and it legitimized it because unfortunately, you know, so much of the time patients' experiences and the experiences of disabled and chronically ill people are written off as, quote unquote, crazy or very unusual or very unlikely, as if that's a reason why we shouldn't care.

And I think that when you have someone at a mainstream media publication or writing at a mainstream media publication saying, you know, this is what I have heard from these people and I'm sharing it. It gives it that kind of stamp of legitimacy, for better or for worse, that allows doctors and politicians and people in power to pay more attention to it.

I remember that there were a couple of people, you know, news anchors who saw my first op ed on Long COVID and reached out to me afterward. And I think about like, you know, the fact that Don Lemon's assistant saw that op ed in the morning and sent it to him. And that is such a small action, but it resulted in, you know, me going on CNN and saying that this is a thing and that young people, you know, can get sick from it, too.

And I have to think that that may have impacted at least one person's decision or even understanding of what they were going through.

00;20;54;20 - 00;21;20;26

Jaime Seltzer

Yeah, absolutely. And I noticed that a lot of the chapters in your upcoming book are written by people with ME like JD Davids and Terri Wilder and Alison Strada. And Body Politic is part of the Long COVID Alliance, which includes #MEAction. Can you discuss why you think integrating the advocacy and disease communities of ME and Long COVID is important?

Yeah. I mean, I wouldn't have understood anything about what was going on in my body if I hadn't connected with people like Terri Wilder and Jen Brea and Alison and other folks in the ME community. My doctor was really wonderful, but she is not an expert on Post-Viral illness.

And so, you know, she's the type of doctor who knows to say, "I don't know" when she doesn't know and knows to defer to my experiences.

But we were really learning together. And so, you know, I was trying to take it easy, but I didn't really know what I was doing. And when I learned about pacing, it helped me kind of put two and two together that, okay, I have this terrible feeling. Well, I just did an hour long Facebook Live event, so that might be part of why I'm feeling really bad right now and I wasn't feeling as bad this morning or even I would have these like super intense waves of fatigue at 4 p.m. every day at 3 or 4 p.m. every day. And if I did more activity, it would hit earlier. Just having a framework with which to understand that and then knowing that there might be ways to mitigate it or feel relief in certain instances was incredibly helpful.

And I just wouldn't have known any of that without the knowledge of people in my community. But people with ME also, I think, really largely shaped Long COVID advocacy and activism because this patient centered, patient like model is obviously what #MEAction is all about. And we had people from #MEAction coming to Body Politic and saying, I have-- you know, I remember Terri Wilder being like, "I have connections to people in New York politics and I think that we should make a PowerPoint presentation and tell them what Long COVID is and tell them how it's related to Myalgic Encephalomyelitis and explain what that is because half of them aren't going to know what it is. And you know, I remember sitting there in front of the mirror practicing how to say it before my interviews because I was like this, this is a key.

But it also opened up the idea. I mean, the ME community was the first community that I personally connected with that really helped me understand this stuff. But I think for many of us, it was a bridge to a larger disability justice communities and disabled and chronically ill communities. And this idea of kind of cross disease solidarity and solidarity among disabled and chronically ill people and I think that helped a lot of us on both a personal and political level.

So I wanted to include it in the book because what I'm trying to do with the book is give people the lifeline that the support group was for so many of us in the interim, while we wait for better care and better financial support and all of that stuff. And I feel like learning for people who have been living with complex, chronic illnesses for a long time is one of the most helpful starting points.

00;24;12;05 - 00;24;21;16

Steven Molony

That's amazing. I think that's great. I wanted to ask you as well about the the Long COVID Survival Guide. Can you tell me a little bit about your experience putting that whole thing together?

00;24;22;03 - 00;24;47;07

Fiona Lowenstein

Yeah, it was it was an amazing project to get to work on. I mean, I feel very humbled by getting to edit folks like Terri and JD who have been doing this work for decades. And I feel like I learned a lot from every single contributor. The goal of the project for me again was to sort of provide that lifeline, that survival guide for getting you through whatever you're going through in your Long COVID journey.

And so I wanted to include as many diverse perspectives as possible because I think it's difficult to have a guidebook for Long COVID just written by one person because our experiences are so different, both in terms of the symptoms folks experience, but also in terms of, you know, whether or not you have faced medical sexism or racism or transphobia or whether or not you are dealing with significant financial issues or have lost relationships with people you love.

I feel like the book we've put together, it covers a lot of those topics, from caregiving relationships to financial stresses, and not being able to work to mental health issues. And I'm hopeful that we've created something where most long haulers will be able to find even just one chapter or one person or one anecdote that they relate to.

You know, the thing that people say, you may have seen this, Jaime, in other support groups or maybe in Body Politic, but one of the things that people say the most often when they join Body Politic, especially at the beginning, but I still see it is, "Wow, I had no idea that there were other people out here experiencing this."

And I do feel like that knowledge that you're not completely alone is often the first step to realizing that, okay, this can be livable, I can survive this. And so I think, you know, livable might not be the right word, but we're at this point in time. Obviously, it can be quite difficult to live with Long COVID, but we're hoping to help people survive long it and so that knowledge that you're not completely alone, that there are other people out there. That's kind of what I wanted to get first and foremost in this book.

But we also, you know, Alison Sabrana is a real expert on disability benefits and all sorts of great stuff that's really helpful for folks dealing with financial stress.

Dr. David Patrino and Dr. Donna Ken Murphy and Rachel Robles wrote a chapter on getting accurately diagnosed, which it has - I have notes written down from it that I'm bringing to my doctors appointments, so I think there's also some really tangible advice in there, as well as kind of giving you that warm hug feeling that the community is here for you.

00;27;04;10 - 00;27;04;28

Steven Molony

That's great.

00;27;04;29 - 00;27;22;27

Jaime Seltzer

Yeah, well, that's really important, right? Like to have both concrete advice, but the solidarity of recognizing that there are a lot of people out there in the same boat, despite how quiet our government institutions have kind of been about it.

00;27;24;13 - 00;27;24;26

Fiona Lowenstein

Yeah.

00;27;25;23 - 00;27;30;25

Steven Molony

Can you tell us when and how and where people would be able to get this?

00;27;31;05 - 00;27;54;06

Fiona Lowenstein

Yeah, definitely. So the book is available for preorder right now, which means you can order it. It will not arrive tomorrow. But if you want to get that checked off your to do list, you can do it now. It's available anywhere they sell books. So Amazon, Barnes and Noble, your local indie bookseller. I'm pretty sure my dad ordered one to Shakespeare and Company in New York City and they were very excited about it.

So anyone who wants to do that, you can do that. But it's coming out November 8th, 2022. So it will be out this fall and hopefully we will be doing some virtual events around it with some of the contributors because there's so much knowledge beyond... The book ended up being a little bit longer than we expected. And I'll say that the other editor and I just really couldn't cut down some of the gems in there.

But there's there's obviously even more wisdom that's not included in the book. As as you both probably know.

00;28;25;19 - 00;28;29;01

Steven Molony

Do you think you'll ever release those other things separately?

00;28;30;17 - 00;28;32;01

Fiona Lowenstein

You mean the, like...

00;28;32;01 - 00;28;33;19

Steven Molony

The ones that didn't make the cut, yeah.

00;28;34;11 - 00;28;57;19

Fiona Lowenstein

You know, there were a couple of really good ideas for chapters that just couldn't be included because of scope and you know, people's timelines and I have encouraged those folks to pitch those as articles to publications and have suggested some context for that. And I would love to see that happen. There's you know-- I won't scoop them here, we'll let them let them write them themselves. But yeah, hopefully we'll be able to share some of those someday.

00;29;03;25 - 00;29;07;18

Steven Molony

Cool! Well, I can't wait to check that out. November, right? November 8th?

00;29;08;03 - 00;29;26;22

Fiona Lowenstein

Yeah. Yeah. I think I'm getting that right. November 8th, 2022. And the links and stuff are on my Twitter and my website if it's hard for anyone to find. But thanks, I'm excited! I'm very excited to see it in book form. I'm like, this is so cool - all my friends in a book!

00;29;26;22 - 00;29;58;28

Jaime Seltzer

I have a slightly more creative question for you and you can hold on to your thoughts for a moment if you want to think about it more carefully. And I-- whenever I talk about misconceptions I ask for people to say the true thing first, because the true thing is what then tends to stick in people's minds.

So with that preface, if you were granted the power to snap your fingers and instantly remove any one misconception about Long COVID, what misconception would you choose and why?

Start with the factâ€”the real thing that is actually trueâ€”and then tell me the misconception.

00;30;07;13 - 00;30;09;06

Fiona Lowenstein

Oof. This is-- there are so many.

00;30;10;23 - 00;30;12;28

Jaime Seltzer

We don't just give the softball questions here.

00;30;14;13 - 00;30;41;21

Fiona Lowenstein

Yeah. Which one is the most-- I mean, this seems so obvious, but there is nothing you can do currently to prevent completely your chances of getting Long COVID. Doesn't matter who you are, who your dad is, who you think you are. I just feel like I see a lot of people on the Internet being very surprised that it happened to them.

And I get that because obviously I felt the same way and I wasn't paying attention before this either to the fact that Post-Viral illness existed, even though I had experienced it in life. I just hadn't realized that at that point. So I guess the misconception is that long COVID only happens to certain people, or that Long COVID can be prevented if you take the right measures or get vaccinated.

And the truth is that long COVID is not currently preventable by vaccines, right? In order for it to be preventable, we have to know that vaccines prevent Long COVID, that you can't get it if you're vaccinated. And it's pretty clear that that's not the case and that it does not discriminate. Your experience might be very different if you are a wealthy white celebrity, but as we've seen, those people can also still get Long COVID.

So I'd say probably that or just the fact that post viral illness exists, that's definitely something that would have helped me earlier in life.

00;31;44;01 - 00;32;14;18

Jaime Seltzer

Yeah, I'm with you there. I think that there is some sort of mystical barrier where people are like, if I see a bad thing, bad things are things that happen to others and not to me, that somehow I have some kind of protective barrier against bad things in life. But yes. And anyone anyone can get Long COVID and I hate to ask you this because this is like a huge project.

You just finished a book, but is there anything that you're currently working on that's new?

00;32;21;12 - 00;32;52;03

Fiona Lowenstein

Well, I've been doing some consulting for JD David's new group, The Network for Long COVID Justice, which has been really exciting. #MEAction is one of the orgs that they're convening, along with Patient Led Research and Body Politic and COVID-19 Long Hauler Advocacy Project and Marked by COVID. So that's been cool. I've also been doing some stories for Business Insider where I'm trying to look more at the relationship between chronic illness and work.

So talking to people right now who have actually successfully accessed good workplace accommodations and trying to learn more about how that happened and if there are tips for others. But I think, you know, I am taking definitely a little breather as we kind of wrap up the book where we're still very much in the process of finishing that project.

But I am hoping-- I've been-- I'm kind of like writing a feature each year for the past couple of years. And I'm, I know I need to start kind of thinking about that and pitching it soon. And I'm also working on an article right now for Teen Vogue. They're doing a disability-- I'm not sure when this episode is coming out, but in August they're doing a disability focused package and there will be a story in there on a dozen or so long haulers about how their lives have been impacted and how their lives have changed.

And I'm really trying to focus on people who haven't been-- groups that haven't been as well represented in media coverage. So people who are disabled and or chronically ill prior to getting Long COVID, communities of color that were hit hard by COVID infection rates, students, trans long haulers, all that stuff.

00;34;05;25 - 00;34;21;02

Jaime Seltzer

That sounds really fascinating. Teen Vogue is-- they've been more and more on the ball, honestly, like the past four or five years. They've just gotten so sharp. Hey, Teen Vogue people, you're very impressive these days. Good for you.

00;34;21;20 - 00;34;41;11

Fiona Lowenstein

You know what I think part of it is, is they have like several disabled writers working with them who do really good stories. And I think they very much understand that having someone who has had personal experience with the topic they're reporting on is not a disqualifier at all and is, in fact, going to often make the story better.

And that's I think that's one way that journalism is changing for kind of my generation right now, at least, I hope.

00;34;48;13 - 00;34;49;10

Jaime Seltzer

And science.

00;34;49;29 - 00;34;51;28

Fiona Lowenstein

Yes. Yes, absolutely.

00;34;52;26 - 00;35;02;07

Steven Molony

This is kind of an open question for you. What is one thing that you would like to share with the wider community of Long COVID and ME?

00;35;03;21 - 00;35;37;23

Fiona Lowenstein

I think, you know, my focus is definitely a lot on media coverage and media. And so I want to talk a little bit about the relationships between or the relationship between sources and journalists and specifically who are long haulers or disabled or chronically ill and journalists who report on them. I think that this is often a tense relationship and that there's a lot of mistrust and distrust in the Long COVID community of journalists because there's been some really terrible coverage of Long COVID, as there's been heinous coverage of ME.

And I think that-- I just-- anyone who's listening to this, who might hear from a journalist, I think it's really important to know that you are in control of your own story, that you have rights as a source, and you can ask a journalist when they reach out to you for examples of other stories that they've written on this topic, you can ask them more details on what the story will look like or what the framing is, or what other sources they're speaking to.

You can ask for modifications in an interview process. Definitely more traditional journalists do prefer quotes that are given over a phone call or a zoom call. But one workaround I've found for that is offering people the option to provide audio messages via text, something you can do over a longer period of time. So, you know, this is kind of in the weeds, but I know there are a lot of long haulers who share their stories online and get contacted by journalists.

It's okay to ask questions of the journalist as well. And if the journalist is not responding in the way that you want to those questions, that may be a sign that this is not the right opportunity for you.

00;36;42;25 - 00;37;05;07

Steven Molony

That's such good advice. Jaime and I-- before this began, we were just talking about that very thing of, you know, talking to journalists, wanting to make sure what the content of the article is going to end up being like. Is it going to misrepresent, you know, whether it's Long COVID or ME or whatever, you know. That's great advice.

00;37;06;02 - 00;37;34;01

Fiona Lowenstein

Yeah. And, you know, you're not always going to be able to predict it 100%. And there are journalists out there who will use slightly shady tactics to try and get information from sources. But I hope and believe that that's not like something that mainstream journalists are doing right now too Long COVID patients. That feels really unethical. And, you know, there tends to be some understanding that if someone is in a vulnerable position, you treat them with a bit more care and transparency about what you're doing.

So I guess it's also important to say that if you've been interviewed by a journalist, an article that came out was just terrible and you feel a lot of guilt about it, understand that that is also not necessarily your fault, right? Like we can't always predict these things or know what quotes people are going to use, or not going to use.

00;37;52;27 - 00;38;19;09

Jaime Seltzer

Absolutely. And it does help to look up their name and, you know, a key phrase or two. And then you can often see the gist, and what kinds of things they write. I would add to that that generally speaking, if somebody presents themselves as a contrarian, I think that that's a bit of a red flag. They find a popular issue and take the opposite stance from the one that seems common sense.

That would be a bad, bad plan to engage someone like that. But definitely it can feel very flattering to, you know, for somebody to reach out to you and say, like, I want to hear your story, especially if the fact is that you feel like people just haven't been listening. So there are shady people out there who are very aware of that vulnerability and happy to exploit it.

But I agree with you that they're in the minority.

00;38;47;13 - 00;39;14;10

Fiona Lowenstein

Yeah. And I think we're also seeing there has been improvement in this coverage over the course of the pandemic where, you know, certain things where people may have taken the bait before, you'll see a little bit more abstaining from reporting on. Obviously, there still there are so many issues. And the thing that drives me just up the wall right now is the the constant reference to Long COVID as utterly mysterious.

There was like an article in Fortune the other day that called it the great enigma of our time. And I was like...

00;39;22;22 - 00;39;50;29

Jaime Seltzer

I mean, I guess that that's like, you know, clickbait in a way. It's like people like something that's mysterious and, you know, feels like watching an episode of House, M.D. How cool. But it also paints it as this practically supernatural entity that no one can ever find anything out about. When in reality, your studies are ongoing. There are similarities to ME which we started the pandemic knowing a bit about.

And I agree that it's just a very strange framing beyond what I just said in terms of like it's clickbait. Why do you think people describe diseases like Long COVID as mysterious?

00;40;02;01 - 00;40;21;24

Fiona Lowenstein

I mean, I think part of it, you know, it's interesting. I did a segment with NPR recently and in the pre interview, one of the things that it was about media coverage and the producer asked me, but what if the the person who's experiencing it feels that it's mysterious or feels that it's, you know, it who's experiencing the symptoms describes it that way?

And I said, well, you know, it's important to be true to their experience as a journalist. Right. And so they're saying this really mysterious and strange thing is happening to my body.

You can see that they find it mysterious and confusing. But then wouldn't the story be why they feel that way if there is information out there on it and why that information made it to them?

Because, you know, that story still really hasn't been written. The story of like why more of us don't know about Long COVID and don't understand it. Right. There's been a lot of stories on Long COVID affects a lot of people. And there have been a few stories explaining that Long COVID isn't new, but no one has actually tracked the health messaging in a mainstream news article online, covered and looked at, you know, where did it go wrong and how is it getting out to people and what's going on here?

Because I personally don't think too many people care as much about that as I do, but I feel like that's a story that should be written.

00;41;16;18 - 00;41;17;05

Steven Molony

Absolutely.

00;41;17;05 - 00;41;39;20

Jaime Seltzer

That is an important story. I can't help but think that it doesn't quite jibe with the CDC's representation of ME as-- Or, sorry-- of Long COVID and COVID in general as mild and you know, please go out and spend more money on things. You're totally safe to spend everything in your wallet today. Sorry.

Cynicism. A little cynicism there, but I can't help. I said just a few minutes ago. A few hours ago. I'm beginning to get tired. You can tell that the CDC has prioritized economic recovery over everything else by so many orders of magnitude, that any story that doesn't really fit with the narrative that we are all safe and there is no war and busing, say, is just really not going to be heeded because the public has now heard that message that you are safe in so many different ways and so many different iterations, that stories that don't jibe with that sort of bounce off of a forcefield.

00;42;26;26 - 00;42;45;26

Fiona Lowenstein

Yeah. And I think that's part of what I was thinking of when you asked me what the biggest misconception is. And I feel like it is that belief in safety because the government has said you're safe and there are people in this country who don't feel that they've been held by the government ever or maybe haven't before in a real way.

And so I think that's why you see that approval rates for mask mandates or wearing masks indoors are typically higher among black and brown communities than they are among white communities. Right there is a certain level of trust in the government, sometimes among people who have not been severely disappointed by it. And it's also just like this deep embolism of like incredibly distancing yourself from any form of disability if you're not disabled or if you don't claim the term disability and just being like that can't happen to me.

That's not going to happen. The CDC thing is also funny because they have been meeting with Long COVID advocates since January of 2021 and Hannah Davis was saying on Twitter recently that the people on those calls take Long COVID very seriously, but it's just not getting into the mainstream pandemic messaging that the CDC is doing.

00;43;38;18 - 00;44;03;16

Jaime Seltzer

The CDC is not a monolith is the problem. You know, there might be individuals there working very hard for people with Long COVID, but unfortunately it doesn't rise all the way to the top. And that's the way it is with a lot of these government organizations that in fact, they tend to put their sweetest, most empathetic, most listening people out in front to interface with patients and advocates.

But it's very challenging to be sure that what you're telling them actually works its way into policy, into actions, even into messaging. I'm glad that the CDC has a page on Long COVID that has been decent, but I do wish it would also enter public messaging that you can have long term effects of of SARS-CoV-2 and that I was going to try and mince words, but I'm not. And they're permanent.

Per-ma-nent. Chronic. Chronic.

00;44;44;12 - 00;44;50;22

Fiona Lowenstein

And these are the ones we know about. These are the ones we have seen in large numbers.

00;44;51;21 - 00;45;37;05

Jaime Seltzer

In my experience, the main barrier is that there are clinicians. They really have trouble accepting that a disease could be ongoing. I don't understand it at all.

I have to say that if I had to interpret that widespread belief that all diseases are cured or kill you, I would say that it's a sign that clinicians are not serving these patients at all and that the patient who sees their clinician and says, I have these ongoing symptoms and the clinician says, That's nice or I can't do anything for you, or I have empathy for you, but there's nothing for me to do or say that patient isn't coming back.

And so the clinician has no sense of how long these symptoms tend to continue. And they think that if the patient doesn't go back, then they must be better.

00;45;50;18 - 00;46;07;07

Fiona Lowenstein

You know, it's funny because a lot of my-- I think the Omicron-- the first Omicron wave and now this wave, is the first time that I've actually had a lot of people in my personal life who didn't have Long COVID before are telling me that they're experiencing long term symptoms. And a lot of them are.

I'm 28, a lot of them are around my age or little younger, and a lot of them don't have PCP's because they just haven't had great health insurance and haven't had a need to go to the doctor regularly or their health insurance changes. And so an interesting byproduct of this is that a lot of them are not going to doctors for advice on their Long COVID symptoms.

They're like looking on Twitter and asking me and going into support groups. And it's I never thought I would be thinking or saying this, but I'm like, yeah, that's actually probably not a bad thing, especially in those first few weeks after the acute phase, which seems to be what we're calling it, even though we don't really know what's what friends and people are like, I'm feeling tired.

I'm thinking, well, at least you're not going to a doctor who's telling you to exercise it all away. So hopefully that's--

00;47;00;25 - 00;47;04;14

Jaime Seltzer

Just think about your symptoms differently and they'll go away.

00;47;04;27 - 00;47;18;05

Steven Molony

So eventually this will be one of those things that people look back on, you know, generations from now and think, what?

What were we doing? You know, like this-- It's like it'll be the equivalent to using leeches for everything, you know?

00;47;19;14 - 00;47;51;17

Jaime Seltzer

People will look back and say... Well, people now aren't that foolish because that's what we're saying now. Yeah, you know, people are people and throughout history, people are going to be peopling and we just have to recognize that we are no smarter than the people. Two or three generations ago who made other clinical errors. We are just as susceptible to bias and just as vulnerable to misinformation and disinformation as we ever have been.

00;47;51;17 - 00;47;55;17

Steven Molony

Maybe even more so with social media being what it is.

00;47;56;00 - 00;48;19;21

Jaime Seltzer

Now that people are getting really good at misinformation and disinformation. Yeah, I agree with you. I think we are actually more vulnerable. And of course, you know, #NotAllDoctors, but the system is set up in a certain way to reward clinicians who are able to hustle the patient out of their office as fast as humanly possible and to reduce the cost of care.

So, you know, and it's one of those things that's true regardless of whether socialized medicine is in the picture.

00;48;28;04 - 00;48;50;10

Fiona Lowenstein

Yeah. And I think that is something that a lot of people commenting on Twitter often miss. Right. You'll see people kind of hearing about long periods of time and going like, this is why we need universal health care. That's like, yeah, give it to me today, but also like our friends in the UK and our friends in all of these other countries with nationalized health care systems are having a pretty terrible time.

And, you know, it can be harder sometimes in those situations if something is-- We have the clinical guidance from the CDC, our doctors even aware of it? Like, are they even paying attention to it? I'm not sure. You know, if they were, would it even matter? It's like, okay. But it also has a lot of, you know, caveats in it.

But then I think about the impact of the NICE guidelines in the UK, especially for ME.

And I think there's, you know, there's just a different set of issues that can crop up in that situation.

00;49;20;27 - 00;50;01;06

Jaime Seltzer

Yeah, absolutely. And you know, just for our listeners who may not be as familiar for a very long time in the UK graded exercise therapy in combination with cognitive behavioral therapy, it was recommended for ME/CFS. Up to 80% of people either do not benefit or deteriorate on GET, CBT, but they kept offering it despite the fact that patients broadly reported that they did terribly, and despite the fact that post exertional malaise is the cardinal symptom of this disease, which is worsening after activity, as Fiona described multiple times over the course of this conversation.

And they've changed those guidelines to eliminate graded exercise therapy and to clarify that cognitive behavioral therapy is supportive, to help you deal with being sick, not to try to convince you that different thinking will banish your sickness. Unfortunately, the NICE guidelines for Long COVID in the UK still recommend exercise, which is wild considering that about half of people with Long COVID meet the diagnostic criteria for ME/CFS.

So hopefully that nutshelled it for you all.

00;50;34;29 - 00;50;38;11

Fiona Lowenstein

That was a great little explainer there.

00;50;38;11 - 00;50;38;27

Steven Molony

Yeah. Great nutshell.

00;50;39;16 - 00;50;58;03

Jaime Seltzer

Yeah but the reason that those therapies were promoted is that they're cheap. If you had mental health issues, you would be recommended nothing because that's the cheapest possible intervention you can get away with. And if you have a physical illness that's chronic complex, you'll be recommended therapy because that's the cheapest recommendation that you can possibly get away with.

00;50;59;10 - 00;51;10;16

Fiona Lowenstein

It's so ironic. It's like therapy is being thrown at long haulers, but also we, like, therapy is so hard to access as well to begin with. And then, you know--

00;51;10;25 - 00;51;12;21

Jaime Seltzer

Just find a therapist. Sure!

00;51;12;26 - 00;51;35;00

Fiona Lowenstein

Yeah, yeah, that's easy. That's something that didn't take me years to do even before COVID. And it's also funny seeing these critics on on Twitter will say that because Long COVID advocates are insisting that Long COVID does not have a psychological root cause, that we are stigmatizing mental illness and the very real physical effects of mental illness.

And this is something my anxious ass never expected to hear.

00;51;40;14 - 00;52;03;00

Jaime Seltzer

That is classic projection. That is classic projection. They are biased against people with mental illness. I don't think those people who are saying that, by the way, are millennials or Gen Z. I think that they deeply believe that it's a humiliating thing to have a mental health diagnosis, and they're projecting that onto the younger generations who are like, you know, you just said my anxious ass, right?

My ADHD ass I will broadly say to anyone who's willing to listen, you know, that I have this thing because it is that's how you find community. That's how you connect with people who share your experiences. That's how you find out things that help you. This idea that, you know, mental health is just so taboo and that's why we're saying it.

I mean, or we're saying it because we don't feel that these symptoms arise from psychiatric ideology that it could just be that. Straight forward, y'all.

00;52;36;08 - 00;52;37;05

Fiona Lowenstein

Yeah. Yep.

00;52;37;21 - 00;52;42;23

Steven Molony

Well, Fiona, thank you so much for hanging out with us on the podcast. We really appreciate your time.

00;52;43;08 - 00;53;08;09

Fiona Lowenstein

Thank you so much for having me. This feels like a real honor as #MEAction was, again, the first door that kind of opened to me in this world. And helped me understand so much about the work that I feel like I'm doing as a journalist, trying to amplify patients' voices. But also, again, just my own life, my family's lives, you know, the ways that friends have been treated in the world.

It just again, this was the kind of key that unlocked a door to a larger framework of disability justice and the larger history of disability rights activists. And so that has been... Thank you all for that.

00;53;22;14 - 00;53;24;17

Steven Molony

Well, we're honored to have you. So where--

00;53;25;07 - 00;53;25;15

Jaime Seltzer

Absolutely.

00;53;25;15 - 00;53;28;18

Steven Molony

Where can people find you online and everywhere else?

00;53;29;10 - 00;53;42;04

Fiona Lowenstein

Yeah. So I'm on Instagram and Twitter. My handle is @Fi_Lowenstein, not going to spell the last name for you, but just type in some letters that sound right. And I'm sure...

00;53;42;11 - 00;53;46;20

Steven Molony

We can put it on our... We'll make sure it's in the description of the episode as well.

00;53;47;08 - 00;53;54;20

Fiona Lowenstein

Cool. Sounds good. And I have a website as well that's linked on that stuff that has some of my writing and more information about the book as well.

00;53;56;01 - 00;54;05;21

Jaime Seltzer

Thank you so much for coming on. It's fascinating to talk to you and fascinating to listen to your thoughts about these sister diseases, as always.

00;54;06;10 - 00;54;11;09

Fiona Lowenstein

Likewise. Thank you so much.

<Theme music plays>

00;54;11;09 - 00;54;14;04

Steven Molony

Thank you so much to Fiona for joining us on the podcast.

00;54;14;14 - 00;54;19;26

Jaime Seltzer

And thank you again to our sponsors at Outside In Theatre and the Goodman Center.

00;54;19;26 - 00;54;32;07

Steven Molony

Don't forget, the Long COVID Survival Guide is available now for preorder and the book will have its full release on November 8th. If you'd like to follow Fiona's wonderful work, check out our episode description to see where you can follow them on social media.

00;54;33;23 - 00;54;45;07

Jaime Seltzer

At #MEAction, we're building a global movement to fight for recognition, education and research so that one day, all people with ME will have support and access to compassionate and effective care.

00;54;45;25 - 00;54;55;13

Steven Molony

If you'd like to stay up to date with what we're up to, visit us at #MEAction.net. Subscribe to our newsletter and follow us on social media @MEActNet.

00;54;56;10 - 00;55;13;04

Jaime Seltzer

If you have any questions or suggestions for guests you would like to see on the show, feel free to email us at podcast@meaction.net. Thanks for joining us at #MEAction's Chronically complex Podcast. Keep reading, writing, speaking out, and speaking up.

00;55;13;12 - 00;55;30;13
Steven Molony

And don't forget to #StopRestPace. We'll see you next time.